



# The Unique Experience of Caregivers of Outpatient Hematopoietic Stem Cell Transplantation (HSCT) Patients: Lessons Learned from the Inpatient HSCT Literature

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## Background

- According to the Oncology Nursing Society, **caregiver burden** encompasses the difficulties of the caregiver role, and associated alterations in the caregiver's emotional and physical health that can occur when care demands exceed resources.
- *Caregivers experience differing challenges during different phases of the cancer trajectory* that can significantly impact their functioning and quality of life.
- Outpatient transplants are becoming increasingly common and may place greater demands on caregivers.
- **The purpose of this systematic review was to synthesize the literature on burden experienced by HSCT caregivers, with an emphasis on the unique burden associated with the outpatient transplant process.**

## Method

- Relevant studies were identified by a database search of Pubmed, Psychinfo, Cochrane, CINAHL, Web of Knowledge, and Embase.
- Key terms included: Caregivers OR Family OR Spouses) AND (Adaptation, Psychological OR Stress, Psychological OR Quality of Life) AND (Bone Marrow Transplantation, Hematologic Neoplasms) AND (informal caregiver OR caregiver OR spouse OR family OR family ) AND (strain OR distress OR stress OR burden OR self neglect OR quality of life OR QOL) AND (BMT OR bone marrow transplant\*)
- Inclusion criteria:
  - Adult caregivers of HSCT patients.
  - Quantitative and qualitative studies.
  - No date or language restriction were applied.

## Results

- The search produced 1,271 articles; 3 additional articles were identified from other sources; 1,134 remained once duplicates were removed.
- Titles/abstracts were reviewed by two independent members of the team; differences were discussed and consensus achieved on 18 studies

**Table 1: Key Study Characteristics (N=18)**

Characteristics	%
Study Design*	
Cross-sectional	39
Longitudinal	44
Qualitative	11
Mixed-methods	.5
Transplant Type	
Allogeneic	17
Autologous	17
Mixed-sample	44
Unspecified	22

\*At data collection. \*Remainder % >100 = Not reported.

**Table 2: Key Caregiver Characteristics (Mean %; N=18)**

Characteristics	%
Demographics	
Age, mean	46
Female	59
High-school graduate	62
Partnered/Spouse	87
Race/Ethnicity	
White	87
Black	7
Asian	6
Hispanic	7
Employment Status	
Full-time	63
Part-time	12
Retired	21
Homemaker	12
Unemployed	23
Relationship to Patient <sup>1</sup>	
Partner/Spouse	94
Parent	28
Child/Sibling/Friend	39
Co-morbid Condition <sup>2</sup>	33

<sup>1</sup>When included by studies. <sup>2</sup>n=3; significant/chronic medical illness outside of cancer.

## Summary of Results

- Participants/Caregivers were predominantly female, White, partnered and employed.
- *Time since transplant and length of caregiving* were not consistently or adequately described.
- The majority of studies evaluated caregivers of patients undergoing HSCT during the acute transplant period where patients were receiving inpatient HSCT.
- No studies examined the experience of caregivers of patients undergoing outpatient allogeneic HSCT.
- One-third of studies included targeted measures of *caregiver burden*.
- **Caregiver burden was not consistently operationalized across studies.**
- 17% of studies included measure of reward/benefit.

## Conclusions/Implications

- Caregiver burden during the inpatient HSCT procedure suggests significant emotional and physical symptoms despite the support of professional staff. More significant burden is therefore likely among caregivers of patients receiving outpatient or homebound HSCT, where caregiving responsibilities are considerably greater.
- The absence of data regarding the unique experience of caregivers of patients receiving outpatient or homebound HSCT is concerning as HSCT in these settings is becoming increasingly common.
- Future research is needed to:
  - Identify caregivers at high risk for burden early in the HSCT process.
  - More specifically characterize caregivers and care-recipients, including clinical factors of the HSCT procedures (e.g., intensity of conditioning).
  - Attend to specific sources of distress and seek to identify time points along the transplant trajectory at which caregivers are at particular risk for burnout and burden.
  - Identify the unique needs of ethnic/racial minority caregivers of HSCT patients.

**Figure 1: Primary Outcomes Examined (% studies that examined outcome)**

